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Year: 2016

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## Public Health and Human Rights

Tasioulas, John ; Vayena, Effy

DOI: <https://doi.org/10.1001/jama.2016.5244>

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ZORA URL: <https://doi.org/10.5167/uzh-135644>

Journal Article

Published Version



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Originally published at:

Tasioulas, John; Vayena, Effy (2016). Public Health and Human Rights. JAMA : the Journal of the American Medical Association, 316(1):103-104.

DOI: <https://doi.org/10.1001/jama.2016.5244>

munity, especially for the donor's family, and must include possible responses to incidental findings. This means there is a responsibility to consider potential downstream effects (eg, heritable diseases) on the families of those who donate their bodies. Issues such as the appropriate acquisition, storage, use, and destruction of the generated information also need to be considered to contribute to a robust and ethical practice framework. Deciding how to proceed should include discussion within the broader academic community, as the mechanisms for how to deal with these issues in the living remain difficult and there is no clear consensus.<sup>4</sup>

Although in the United States, as the authors stated, there are no legal or regulatory hurdles when using cadaver tissue (because human research regulations only cover living individuals), this is not the case worldwide.<sup>5</sup> Irrespective of the legal aspects, however, the ethical aspects of using human tissues that were altruistically donated for medical education need to be at the forefront when considering the use of this technology.

The motivation for medical education to include practical experience of genetic testing has merit. We urge caution with respect to the use of this new technology in medical education wherein willed bodies are involved, and suggest wide consultation is required to develop appropriate ethical practices for this purpose.

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**Conflict of Interest Disclosures:** The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr Winkelmann is the chair and Drs Cornwall and Hildebrandt are members of the Federative International Committee for Ethics and Medical Humanities of the International Federation of Associations of Anatomists. No other disclosures were reported.

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2. International Federation of Associations of Anatomists. Federative International Committee for Ethics and Medical Humanities. <http://www.ifaa.net/index.php/ficem>. Accessed January 16, 2016.
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4. Hehir-Kwa JY, Claustres M, Hastings RJ, et al. Towards a European consensus for reporting incidental findings during clinical NGS testing. *Eur J Hum Genet*. 2015;23(12):1601-1606.
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**In Reply** We could only briefly highlight key ethical issues pertaining to the use of exome sequence data obtained from individuals who have donated their bodies for teaching anatomy to medical students in our Viewpoint, which Dr Cornwall and colleagues have described in more detail.

Although not required, our program is fully compliant with the International Federation of Associations of Anatomists' guidelines and incorporated guidance from our institutional review board regarding both the use of DNA from cadavers and the reporting of an educational initiative. Part of our intent was to generate interest and discussion in this area, for which, as Cornwall and colleagues point out, only a paucity of ethical guidelines and thought exists. The consent for total body donation to the Humanity Gifts Registry of the Commonwealth of Pennsylvania<sup>1</sup> allows for use for anatomical study, research, or both. However, it also states that "no reports will be provided to the family." We are thus precluded from returning results based on incidental or secondary findings. Indeed, a genetic disease in the donor with implications for relatives may be found through the discovery of anatomical and pathological findings during dissection without any genetic analysis. Our program is also not conducted under clinical grade standards and regulatory requirements, which would require substantial additional resources to be a diagnostic program. Even with DNA sequencing performed for clinical care, a consensus does not yet exist on which incidental or secondary findings should be returned to patients, practical guidance is limited, and national and international standards are lacking.<sup>2</sup> Despite these deficiencies, such testing is growing substantially.

We agree with Cornwall and colleagues that the merit and value of our approach warrant more work to identify best ethical practices. However, we believe more data are required before a consensus based on the "wide consultation" suggested by Cornwall and colleagues can be reached. Multiple stakeholders accruing real-world experience in a diversity of settings and using various approaches are needed, as well as funding to support research into the ethical, legal, and social implications of this type of educational initiative.

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**Conflict of Interest Disclosures:** The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

1. Humanity Gifts Registry. Through generosity knowledge grows. <http://www.hgrpa.org>. Accessed March 17, 2016.
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## Public Health and Human Rights

**To the Editor** Dr Galea and Mr Annas called for greater priority to be given to public health vs more individualized methods to improve population health.<sup>1</sup> We agree with the authors' recommendation for a multisectorial approach to public health that engages academia, industry, and the not-for-profit sector. We wish to highlight, however, the authors' proposal

that the Universal Declaration of Human Rights (UDHR) should be formally adopted as the code of public health ethics. Although we endorse the public health role of human rights,<sup>2</sup> an exclusively rights-based approach generates 2 serious challenges that the authors did not address.

First, it is widely assumed that human rights, including canonical instruments such as the UDHR, apply exclusively to states. This assumption seems to be shared by the authors when they wrote that human rights are appropriate to public health because “much of public health is still directed by governments.” But their focus on “governmental obligations” is in tension with their recommendation for a multisectorial strategy. Mobilizing human rights for public health needs to reflect the fact that human rights obligations extend beyond the state, encompassing many kinds of nongovernmental actors. A recent example of this is the United Nation’s Guiding Principles on Business and Human Rights,<sup>3</sup> which directly impose on corporations a responsibility to respect all human rights, including the right to health.

Second, the authors did not address the potential tension that exists between human rights and public health. Human rights are individualistic in focus, being concerned with claims that individuals can make to the provision of certain benefits. By contrast, public health is geared toward aggregate health goods delivered to populations as a whole. Therefore there is a serious question to what extent a code of human rights alone can be a comprehensive ethical basis for public health.<sup>4</sup> For example, a common good such as widespread participation in physical activity is vital to population health, but not something that can be completely guaranteed by upholding human rights. Examples such as this suggest that considerations of the common good in addition to human rights will be needed when seeking an ethical basis for public health.<sup>5</sup>

Human rights are important to public health, and their importance extends beyond governments, but the ethics of public health need more than human rights.

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**Conflict of Interest Disclosures:** The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

1. Galea S, Annas GJ. Aspirations and strategies for public health. *JAMA*. 2016; 315(7):655-656.

2. Gostin LO. *Global Health Law*. Cambridge: MA Harvard University Press; 2014.

3. United Nations Human Rights Office of the High Commissioner. *Guiding Principles on Business and Human Rights*. New York, NY and Geneva: United Nations; 2011.

4. Childress JF, Faden RR, Gaare RD, et al. Public health ethics. *J Law Med Ethics*. 2002;30(2):170-178.

5. Tasioulas J, Vayena E. Getting human rights right in global health policy. *Lancet*. 2015;385(9978):e42-e44.

**In Reply** Our Viewpoint made a specific proposal: “Formally adopt the Universal Declaration of Human Rights as the Code of Public Health Ethics.” Drs Tasioulas and Vayena seem to want to disagree, but ultimately provide additional support by asking us to comment on “2 serious challenges.”

First, it is true as a matter of law that human rights obligations are primarily state obligations. Nonetheless, non-state actors, including corporations, nongovernmental organizations, and even intergovernmental organizations like the World Health Organization, can adopt human rights in general or the UDHR in particular as their ethical code.<sup>1,2</sup> These actors do not have the same legal obligations as governments to respect, protect, and fulfill human rights, but certainly can voluntarily agree to use them as their ethical guide. The World Health Organization, for example, states in its 2005 *International Health Regulations*: “The implementation of these [r]egulations shall be with full respect for the dignity, human rights, and fundamental freedoms of persons.”

Second, the claim that human rights, because they are individualistic, are in tension with public health is widely stated in theory but not documented in practice. Human rights and public health share the same goal, which is human flourishing.<sup>3</sup> It is true that public health works on the population level, but many human rights do as well. There are different categories of human rights in the UDHR: articles 3 through 11 are about life, liberty, and personal security (and are the most individualistic); articles 12 through 21 address rights in civil society and the polity; and articles 22 through 27 concern economic, social, and cultural rights.<sup>4</sup> The latter include broad population-based rights, including the right to social security, work, rest, a standard of living adequate for health and well-being, education, and participation in cultural life and scientific advances. Childress and colleagues<sup>5</sup> is cited for the proposition that human rights may not provide a “comprehensive ethical basis for public health,” but the authors of that article never explicitly say that, instead suggesting only that “sometimes” it may be that “a society cannot simultaneously realize its commitments to public health and to [human rights]....” This argument is not about human rights as a guide but about its ability to provide a solution to every complex dilemma.

Human rights are based on the human dignity of all without discrimination. They are about the good of everyone and can (and should) be used by public health “in ways that directly promote population health and advance social justice.”<sup>6</sup>

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**Conflict of Interest Disclosures:** The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

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4. Glendon MS. *A World Made New: Eleanor Roosevelt and the Universal Declaration of Human Rights*. NY: Random House; 2001:172-191.
5. Childress JF, Faden RR, Gaare RD, et al. Public health ethics. *J Law Med Ethics*. 2002;30(2):170-178.
6. Galea S, Annas GJ. Aspirations and strategies for public health. *JAMA*. 2016;315(7):655-656.

## CORRECTION

**Misspelled Author Name:** In the Infographic "Eligibility and Coverage Trends in Employer-Sponsored Insurance," published in the May 3, 2016, issue of *JAMA*,<sup>1</sup> an author's surname was spelled incorrectly. This article was corrected online.

1. Long M, Rae M, Claxton G, Jankiewicz A, Rousseau D; Kaiser Family Foundation. Eligibility and coverage trends in employer-sponsored insurance. *JAMA*. 2016;315(17):1824.

**Additional Author Affiliation:** In the Original Investigation "Antiplatelet Therapy Duration Following Bare Metal or Drug-Eluting Coronary Stents: The Dual Antiplatelet Therapy Randomized Clinical Trial," published in the March 17, 2015, issue of *JAMA*,<sup>1</sup> one of the authors was missing an institution from his affiliation. This article was corrected online. This article was also corrected in April 2015 for errors in describing the prespecified analyses.<sup>2</sup>

1. Kereiakes DJ, Yeh RW, Massaro JM, et al. Antiplatelet therapy duration following bare metal or drug-eluting coronary stents: the Dual Antiplatelet Therapy randomized clinical trial. *JAMA*. 2015;313(11):1113-1121.
2. Incorrect representation of analyses [correction]. *JAMA*. 2015;313(21):2185.

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